

# Cystic Fibrosis WA (Inc)

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## Minutes of the Annual General Meeting

Held at

The Niche 11 Aberdare Road Nedlands WA 6009

(and via MS Teams videoconferencing)

Wednesday 14<sup>th</sup> June 2023

Commencing 6:00pm

### Present

Marija Andacic, Lisa Bayakly, Amanda Bearcroft, Caz Boyd, Brooke Camfield, Matthew Casey, Rachael Clifton, Steffan Crausaz, Sharon Dewar, Julie Foott, Doug Forrester, Alexia Foti, Deidre Gorrie, Gillian Hoyland, Joshua Iszatt, Anthony Kicic, Bob Laing, Gail Laing, Ingrid Laing, Kak-Ming Ling, Renee Ng, Damien O'Reilly, Ric Reyerson, Sally Rose, John Rothwell, Feliciano Sanchez, Linda Smith, Rowena Smith, Sarah Thomas, Vanya Tierney-Sanchez, Samantha Wallace, Chelsea Weaver

### Apologies

Apologies were received from:

Liz Balding, Nigel Barker, John Berens, Shirley Berens, Fiona Byrne, Michelle Buck, Mitch Messer, Siobhain Mulrennan, Raewyn Plackson, Nicole Posa, Colin Savory

### Welcome

CFWA CEO Lisa Bayakly (LB) welcomed those present to the Annual General Meeting, then introduced the guest speaker, Assoc Prof Anthony Kicic, Head of Airway Epithelial Research, Telethon Kids Institute (TKI), and members of his team: Renee Ng, Kak-Ming Ling, and Joshua Iszatt.

### Guest Speaker

AK thanked those present for the opportunity to speak at CFWA's AGM and spoke of his team's current research into treating anti-microbial resistance (AMR), noting that many people with cystic fibrosis develop infections soon after birth. With most of these infections colonizing the lungs; prevention is paramount to long lung lives. Traditionally, antibiotics have been used to treat these infections, however antibiotic resistance has become a significant concern globally.

TKI is well advanced in pursuing bacteriophage as a means to specifically target harmful bacteria and eradicate it. Bacteriophage – a virus commonly found in the environment which infects and replicates within bacteria – injects itself into the bacteria, clones itself and essentially bursts the bacteria through critical mass. AK noted that there are various layers of governance and ethics approval that are being worked through by the team.

AK then called on JI who spoke of a bacteriophage library of phage genomes. TKI sequence DNA, check for harmful compounds, and take high-resolution photos to build a phage genome. Through this process, they ensure integrity by using only published records. JI noted that there are currently 20 different classes of bacteriophages with >90% containing zero genes associated with harm to humans.

JI then called on KML who spoke of pre-clinical testing of phages binding to mucus and their interaction with airway cells. KML also spoke of bacteriophage matching – identifying which phages have different effects on which bacteria strains.

AK added that the TKI research team are researching the use of artificial intelligence (AI) to accelerate the matching process. Currently, it takes up to 4 days to match phages in the lab, with AI potentially reducing this timeframe to within hours. TKI is currently seeking funding to optimize this matching process, adding that cost savings to the health system would be significant.

AK called on RN to speak of phage use going forward, including the testing of using phages with other treatments such as phages with adjuvants, phages with antibiotics, and phages with other phages. RN noted that phages have shown no decline in stability over time i.e. there is no expiry date, unlike antibiotics.

RN concluded with noting TKI's collaboration with RPH to build the infrastructure to bulk produce phages; however, they are still awaiting governance approval from RPH, as well as FSH and PCH. Governance approval for phage therapy treatment in suitable cystic fibrosis patients has been obtained from SCGH.

### **Vote of thanks**

LB extended a vote of thanks and then opened the floor to questions.

Brooke Campbell asked whether phages could be used to treat non-TB avium and abscesses. Anthony responded that they are developing a new library for these bacteria and are currently seeking funding.

Amanda Bearcroft queried whether phages could be used on viruses such as the flu or COVID. Anthony responded that phages will not target viruses, only bacteria, however, they may dampen the viral effects on the body whilst having phage treatment for a bacterial infection. AK added that phages act within 24-72 hours of injection, unlike an antibiotic course which could be weeks.

Steffan Crausaz queried whether clinical practices of phage therapy outside WA exist. Anthony noted that globally, it depended on the country. Phage treatment is highly tailored and commercialized in the US, however, in Europe – led by Belgium – commercialization is not the case, with phage treatments available through public health. In Australia, Westmead is leading the way with treatments already in place; however, the push to larger national clinical trials costs millions and funding is currently being sought.

Lisa Bayakly queried how many phage genomes are available? Joshua answered that there are over 20,000 currently, with phage matching taking a personalised approach. There are currently over 4,000 phage matches in the TKI library.

Feliciano Sanchez asked for AK to comment on the urgency of phage therapy given the rising risk of AMR. Anthony responded that phage treatment depends on the bacterial species which is infecting the patient; some bacteria resist all treatments which only heightens the need for alternatives such as bacteriophages, hence their commitment to research in this field.

Julie Foott asked whether scientists share the phage library globally or do they 'simply go out and find them in the environment'. Anthony responded affirmatively; they simply go out and find phages in the environment. For this reason, TKI is in partnership with the Water Corporation to source "superhero" viruses from water and water treatment facilities.

LB then thanked AK and his team for their commitment to this vital research and their presentation; and the audience for their questions.

LB officially opened the AGM, declared quorum, and noted Ingrid Laing held five proxies.

### **Confirmation of Minutes of AGM held 15 June 2022**

The minutes of the previous meeting had been tabled. It was moved that the minutes be accepted as a true and correct record.

**Moved** Damien O'Reilly

**Seconded** Sally Rose

**For:** all

**Against:** 0

**Abstentions:** 0

**Approved and carried**

### **Business Arising**

There was no business arising from the minutes of the AGM held on Wednesday 15 June 2022.

LB then called upon CFWA President DO to present the President's Report.

### **President's Report**

DO welcomed everyone present to the 2022 Annual General Meeting.

DO noted the board's focus on ensuring CFWA meets community needs whilst managing its governance obligations. CFWA is fortunate in WA to be able to provide a range of services, given its established capability in service delivery and fundraising, alongside the support of the Department of Health WA, the Telethon Trust, the Stan Perron Foundation and Lotterywest.

Demand for services was high in 2022 in what was a challenging year for many individuals and families that CFWA supported. The CFWA team managed the many changing COVID rules and risk levels affecting major changes in fundraising and operations, whilst concurrently delivering on significant new contract commitments.

Difficult decisions were made such as moving many services to remote earlier in the year than planned. However, critical needs were met. DO thanked all the clients and collaborative partners – including the tertiary hospitals and research teams – for their flexibility, as these deliverables could not have been achieved without their support.

DO recognised the CFWA team's collaboration with the CF community and the Federation of CF organisations nationally. In 2022, a major milestone was achieved together with the PBS listing of Trikafta® for eligible patients, initially 12 years plus, who have at least one F508del mutation (from 1 April 2022). CFWA actively supported the CF community with advocacy at state and federal levels and with awareness-raising through media. Subsequently, CFWA was relieved and delighted to see access extended to the 6-11-year-old age group in May 2023.

DO then thanked the Patron John Rothwell and his fellow board members for their support, particularly Vice-President and Treasurer Sally Rose. DO extended his thanks to include new and former board members Linda Smith (who joined in Sept 2022), Amanda Bearcroft (who resigned in Jan 2023), and former board member

Rachael Hosking who lost her battle with cancer in May 2023. Rachael served on the board for over 12 years until 2021 and was greatly valued for her insight, professionalism, and passion.

Finally, DO thanked Feliciano Sanchez, noting this would be his last AGM as a CFWA board member. FS has served on the board since 2006 including six years as President / Vice-President. FS will continue to contribute to the board, particularly to the research working group, and will continue to serve on the board of Cystic Fibrosis Australia.

On behalf of DO, RR presented Feliciano and his wife Vanya with a gift of thanks on behalf of the board and the CFWA team for their many years of service and support.

## **CEO's Report**

LB thanked DO for his presentation.

LB noted 2022 was a challenging year for the CF community and CFWA, with COVID at its peak creating risks, gaps in staff availability and impacts on services.

LB thanked members and stakeholders for their support to CFWA and flexibility, including CFWA's clients, the Patron, the board, the hospital and research teams, and staff.

With ever changing COVID rules playing havoc in the first six months of 2022, LB noted it was 'all hands on deck', backfilling gaps, chasing PPE (protective equipment), managing exposures and so on.

The second half of the year was then a sprint to reconnect with families, and deliver events and programs that had been postponed during the first half of the year. By year end, CFWA delivered an increase in occasions of service to those with CF and their families, and hosted over 30 events, including new offerings.

LB noted the team's commitment and agility in handling the changing situation through the year.

LB added that from her interactions there is still a limited understanding of cystic fibrosis in the wider community, notwithstanding all the awareness and education efforts. When there is greater understanding, a flow on effect of a greater desire to support people with CF through volunteering or donating takes place. CFWA's aim is to improve how we better communicate and convey the complexity of CF and its impact of the individual and those around them. Examples include sharing personal stories in awareness raising campaigns and including more information about CF and its impact in the annual report and funding conversations. Additionally, with the onset of new treatments, CFWA's priority is to ensure it meets the ever-changing needs of those with CF. In 2022, changes included the restructuring of the services team and offerings, the introduction of individualised school action plans, videoconference sessions for youth, and increased wellbeing supports.

Advocacy was strong in 2022 and CFWA celebrated the news of extended access to Trikafta® to those over 12-years of age; this was extended further to include 6-11-year-olds in May 2023. In 2023, CFWA will continue to focus on access to better treatments for all people with CF, the emerging needs for those post-Trikafta® access and more broadly, on the needs of the ageing CF population.

CFWA continued to invest in Post graduate Top Up Scholarships in 2022, as well as opened up grant funding to a broader group through an advertised Innovation Grant designed to attract expertise and drive innovative projects which will enable breakthroughs in CF research; the Innovation Grant was awarded in the first quarter of 2023.

LB finished with highlighting the growth in partnerships and fundraising in 2022 with a very strong \$800k fundraising outcome despite the COVID restrictions early in the year. Commitment and creativity to deliver fundraising events were highlighted, notably around the 65 Roses Day campaign with the virtual rose garden, and the community actively taking part in wrapping roses at home. Partnerships were expanded in new areas such as chronic wet cough education with the Wal-yan Respiratory Centre, Telethon, and other generous partners. Relationship and partnership building will continue in 2023 to grow CFWA's network of supporters.

In closing, LB thanked the team and supporters for their collaborative efforts in 2022 which enabled more people to benefit from services and receive the support they need.

LB then called upon Sally Rose (SR) to present the Treasurer's Report.

### **Presentation 2022 Audited Accounts and Treasurer's Report**

Sally Rose (SR) presented the audited accounts and Treasurer's Report for 2022.

SR noted that the financial performance continued to be well managed, ensuring ongoing sustainability of services to people with CF and other respiratory conditions, despite the COVID-related challenges in 2022.

During the year, the financials were impacted on other fronts including a reduction in contract funding from the Department of Health WA, increased operating costs, and decreased fundraising, donations, and investment income. Fortunately, CFWA holds reserves for such situations and CFWA was able to continue services with minimal disruption.

CFWA's overall result was a net loss of just over \$119k on a turnover of \$2.1m in 2022, against a budgeted loss of just under \$82k on comparable turnover. The total loss was heavily impacted by a \$103k loss in the fair value of CFWA's investment portfolio which has to be recognised in the income statement even though it is not yet realised (per accounting standards). Despite the upheavals of the year, CFWA maintained suitable cash and reserves, with close to \$1m held in cash or cash equivalents at year end.

The operating result (i.e. excluding other income and costs, such as investments) was well managed, with most of the income decline offset by successful fundraising and cost containment. Each of the major fundraising events exceeded budget, including the John Gillard Family Cystic Fibrosis Golf Classic fundraiser, 65 Roses Day, and the Matched Giving Day. Funds were bolstered by multiple community fundraisers with the year on a high with the above-budget performance of the Albany Christmas Lights for CF.

In 2022, CFWA continued to fund and promote CF research with a \$37k provision made for a PhD Top Up Scholarship and \$60k for further research. CFWA also contributed to funding of the CF Federation's important work in advocacy, community engagement and representation, and enhancing CF knowledge and standards of care.

SR noted that financial accounts are regularly reviewed by both management and the board to ensure the costs of running the association, and delivering services, are properly measured and managed in line with revenue raised.

Consequently, SR was pleased to report the finances of the association continued to be managed in a manner which supports the objectives of CFWA.

The financial statements for the year ending 31 December 2022 were audited by Ms Nikki Shen of Hall Chadwick and approved by the board of CFWA. Signed copies are available for inspection by members and will be lodged with the ACNC following the AGM.

In closing, SR acknowledged the efforts of the CFWA team.

### **Appointment of Auditors**

LB proposed that Hall Chadwick be appointed as the auditors for Cystic Fibrosis WA in 2023.

**Moved** Sally Rose

**Seconded** Damien O'Reilly

**For:** all

**Against:** 0

**Abstentions:** 0

**Approved and carried**

### **Elections or Declaration for the Board of CWFA**

In accordance with the constitution, nominations had been called for to fill four two-year vacancies on the board.

Nominations closed at 6pm on Monday 12 June 2023. At that time, nominations had been received from the following to fill the two-year vacancies:

- Sally Rose
- Linda Smith
- Ingrid Laing

There being no surfeit of nominations over vacancies there was no need for an election and those people nominated were declared duly elected.

### **General Business**

There was no general business.

### **Questions from the Floor**

LB called for questions from the floor, of which there were none.

### **Close of Meeting**

LB thanked everyone for attending and supporting the organisation.

There being no further business, the meeting closed at 7.20pm.

*Signed as a True and Correct Record*

Name \_\_\_\_\_ Date \_\_\_\_\_